

Congress of the United States

Washington, DC 20515

March 31, 2004

The Honorable Ralph Regula, Chairman
House Appropriations Subcommittee on
Labor, Health and Human Services, and Education
2358 Rayburn House Office Building
Washington, DC 20515

The Honorable David Obey, Ranking Member
House Appropriations Subcommittee on
Labor, Health and Human Service and Education
1016 Longworth House Office Building
Washington, DC 20515

Dear Chairman Regula and Ranking Member Obey:

On behalf of the ever-increasing number of Americans diagnosed as having autism or an autism spectrum disorder (ASD), we are writing to thank the committee for your previous support for increasing federal funding for invaluable autism surveillance, research, and early intervention initiatives. We are also asking that as you assemble the Fiscal Year 2005 Labor, Health and Human Services, and Education Appropriations bill, you will support our request to further increase funding for these projects.

As in the past several years, the linchpin of our autism efforts is the ongoing monitoring and epidemiology project being coordinated by the Centers for Disease Control and Prevention (CDC). Right now, surveillance centers (which were mandated by Title I of the Children's Health Act), are operating in 17 states and the city of Atlanta. The centers and their staffs are doing their best to collect the available data to assemble a clearer picture of our nation's autism epidemic.

With autism diagnoses continuing to rise at an alarming rate, and the nation's cost of caring for these cases increasing as well, we strongly believe we have no choice but to make this critical investment now rather than later. Right now, 1 million to 1.5 million Americans are living with either autism or an autism spectrum disorder (ASD); and a new case occurs in an estimated 1 of every 250 births. Nearly 120,000 students diagnosed with autism were enrolled in our nation's schools last year, up from only 20,000 less than 10 years ago. And the number of autism cases reported to the California Department of Developmental Services doubled over the past four years, increasing by more than 630 percent over the past 15 years. Nationwide, the U.S. Department of Education estimates that autism diagnoses are increasing by 10 to 17 percent each year.

To ensure that this surveillance can continue and be expanded, we are requesting that the committee increase the surveillance budget from \$12.5 million in FY 04 to \$22.5 million in FY 05. This proposed increase of \$10 million will be put to the following use:

- **Continuing and expanding research** – About \$8.6 million above the FY04 funding level is to be invested in research work, allowing researchers and scientists to review the data to find a cause or trigger for autism, such as genetic markers or exposure to environmental contaminants. About \$2 million of this appropriation would be specifically invested to conduct a pilot program in Georgia with the goal of screening children as early as possible and before the age of 5 for a variety of

developmental disabilities. After the initial pilot program, it is hoped that this screening initiative could be expanded to an on-going, multi-state campaign to increase early detection.

- **Continuing and expanding surveillance** – about \$1.4 million above the FY04 funding level will be invested in the 18 centers to ensure each can do its job collecting and analyzing the data collected. While the U.S. Department of Health and Human Services and the Department of Education are not in agreement on the appropriate procedure for data collection at these centers; the centers and their staff are doing their best to continue this critical work of collecting the available data to assemble a clearer picture of our nation's autism epidemic. This funding would also enable the establishment of additional centers as warranted, especially in regions of the country where no data is currently being collected.


In addition to support for the autism surveillance and research project, we are also asking that the committee build on last year's initial \$2 million appropriation for the National Center on Birth Defects and Developmental Disabilities' (NCBDDD) Autism Awareness and Education Campaign by funding the project at an additional \$3 million.

The Autism Awareness and Education Campaign, also authorized by the Children's Health Act, received its initial appropriation in FY 04. This initiative will focus on better informing and educating parents and the medical community about the importance of seeking early diagnoses of autism. It will work to educate parents as to possible signs of autism and ASD so that they will seek a prompt diagnosis, which in turn should help their child receive the specialized therapies and education that research has shown to be very effective in treating people with autism.

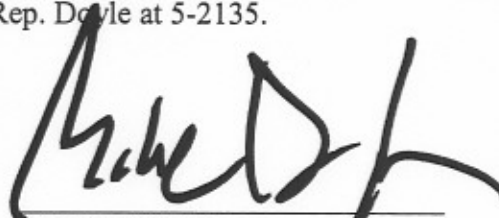
In addition to support for the specific funding requests for the CDC initiatives, we are also asking that the committee provide as substantial an increase as possible to the National Institutes of Health so that it could sustain and advance its critical portfolio of research into autism. To show you just how far we have come, 10 years ago, in FY 1995, the NIH invested about \$10.5 million into autism research. The estimated budget for autism research in FY 04 is nearly 10 times that amount -- \$96.5 million.


NIH funds are supporting eight national autism centers of excellence, known as Studies to Advance Autism Research and Treatment (STAART Centers). The NIH also supports nine Centers for Program Excellence in Autism (CPEAs), which are working to develop and implement a nationwide autism database. Additionally, we need to increase NIH program dollars so we can begin to fully implement, as soon as possible, all of the components of the autism matrix that was released to much acclaim this past fall.

On behalf of the autism community, we again thank you for your past support and look forward to your continued assistance this year. If you have any questions, please do not hesitate to contact us or Nick Manetto with Rep. Smith at 5-3765 or Mike Mullen with Rep. Doyle at 5-2135.

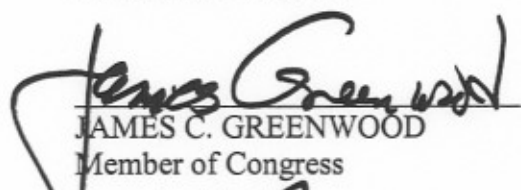

CHRISTOPHER H. SMITH
Member of Congress

Sincerely,

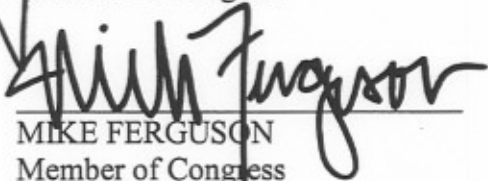

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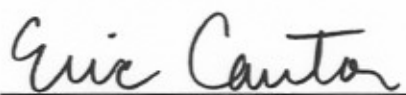
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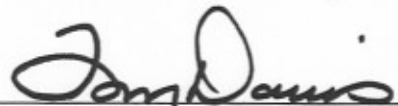
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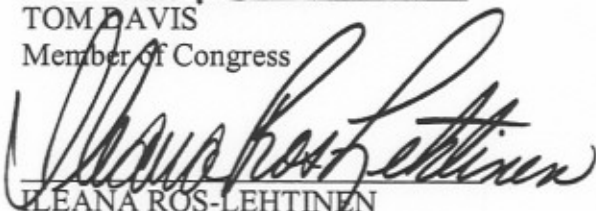
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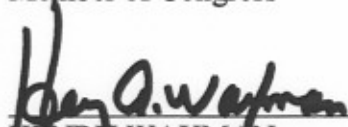
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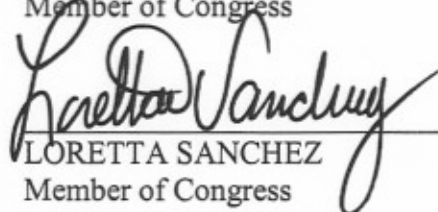
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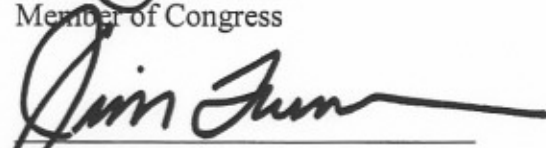
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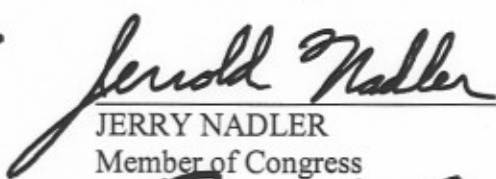
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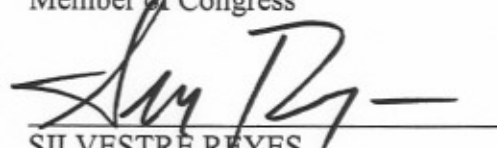
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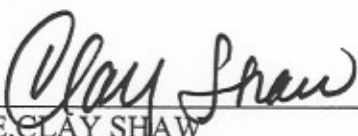
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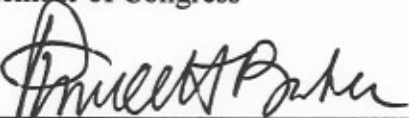
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March 31, 2004

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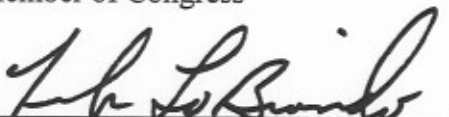
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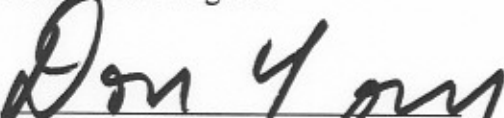
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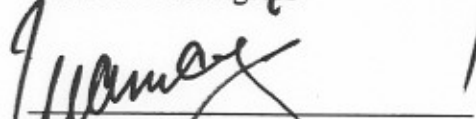
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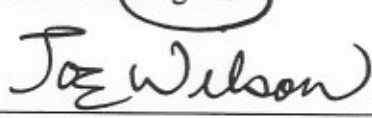
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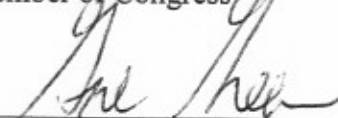
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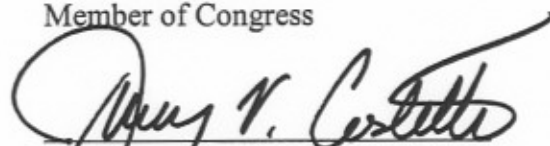
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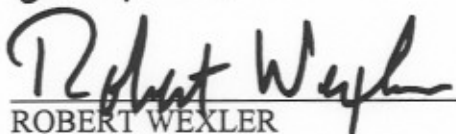

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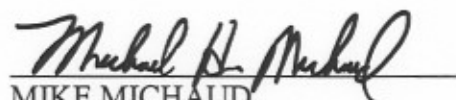

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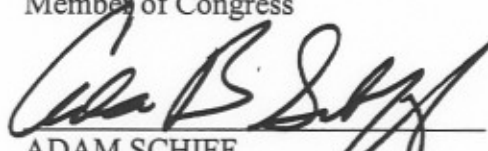

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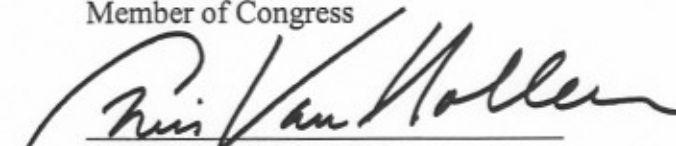

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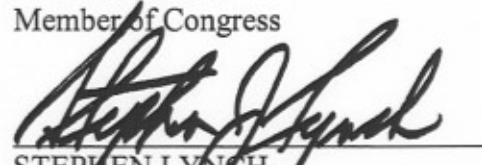

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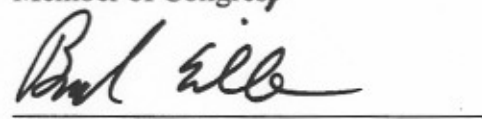

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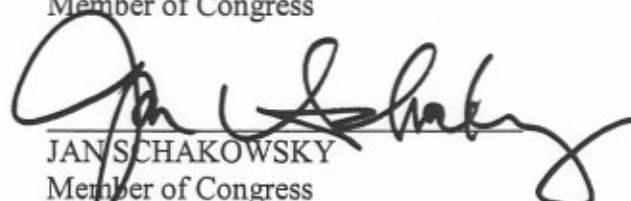

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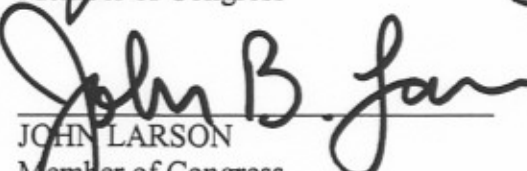

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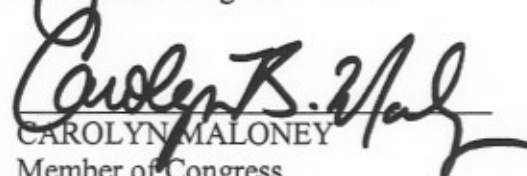

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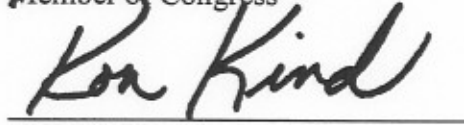

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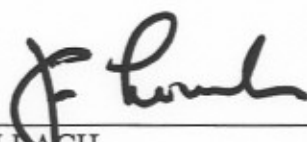

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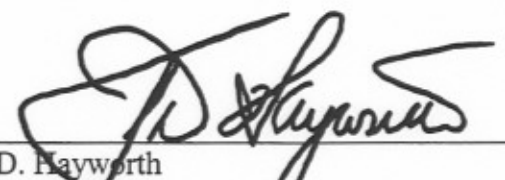

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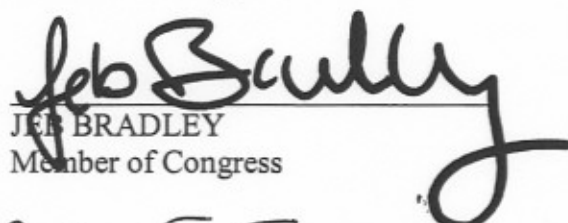

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JIM LEACH
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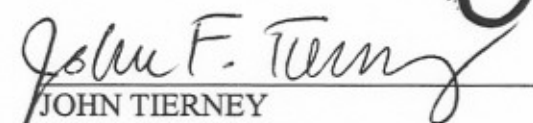
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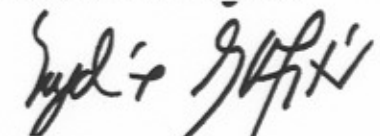
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Wm. Lacy Clay
WILLIAM LACY CLAY



ANTHONY WEINER
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NYDIA VELAZQUEZ
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Suggested FY 05 Report Language for Autism

Centers for Disease Control and Prevention

National Center on Birth Defects and Developmental Disabilities

Autism. The Committee is aware of the progress that has been made with the autism programs at the National Center on Birth Defects and Developmental Disabilities. The Committee acknowledges the importance of this work by the Center in the area of autism surveillance and research, and urges this work to continue in a timely manner. Within funds provided, \$10,000,000 in new funding is available to fund the Center's autism epidemiology program including the CADDRE and ADDM Network. The Center is encouraged to build on these activities by devoting \$3,000,000 in new funding to build upon last year's launch of the Autism Awareness and Education Campaign.

NATIONAL INSTITUTES OF HEALTH

OFFICE OF THE DIRECTOR

Autism Spectrum Disorders. The Committee is encouraged by the NIH's autism research matrix and urges NIH to devote sufficient resources to this research agenda. The Committee urges the NIH when implementing the autism research matrix to coordinate with autism organizations already funding research initiatives to ensure the most efficient use of its resources. The Committee also notes the promise of particular areas cited in the matrix, including genetic and behavioral characterizations of the disorder and screening and early diagnosis.